

# When the Caregiver Needs Care: The Plight of Vulnerable Caregivers

Maryam Navaie-Waliser, DrPH, Penny H. Feldman, PhD, David A. Gould, PhD, Carol Levine, MA, Alexis N. Kuerbis, BA, and Karen Donelan, ScD

An estimated 15 million to 25 million adults in the United States currently provide informal care (i.e., unpaid care) to relatives and friends.<sup>1–3</sup> Recognition of informal caregivers' contributions was heightened recently by estimates that project the economic value of their services to be \$196 billion,<sup>4</sup> a figure that far exceeds national spending for home health care and nursing home care. With ongoing public and private sector efforts to limit post-acute and long-term care payments, the health care system's reliance on family caregivers will inevitably intensify.

Although informal care can positively affect the physical and psychological well-being of care recipients, its provision often comes at a personal cost to the caregiver. Past studies have shown that caregiving can adversely influence the caregiver's psychological health through added strain,<sup>5</sup> stress,<sup>6,7</sup> and depression.<sup>8</sup> Moreover, family caregivers are less likely to engage in preventive health behaviors<sup>9–11</sup> and may even be at increased risk for mortality.<sup>12</sup> However, these effects are not the same for all caregivers.<sup>6,12–14</sup> For example, it has been suggested that certain factors such as race, advanced age, employment status, and inadequate social support increase the caregiver's risk for poor health outcomes.<sup>7,15–19</sup> Therefore, it appears that the added burden of caregiving may have a more severe impact on the well-being of particular subgroups of caregivers who have predisposing characteristics that place them at "higher risk" for adverse health outcomes.

Past studies have rarely focused on high-risk caregivers per se or the nature of their caregiving tasks. The purpose of this study was to examine the characteristics, activities, and challenges of high-risk informal caregivers.

## METHODS

### Study Design and Sample

Random-digit dialing was used to conduct telephone interviews with a nationally repre-

**Objectives.** This study examined the characteristics, activities, and challenges of high-risk informal caregivers.

**Methods.** Telephone interviews were conducted with a nationally representative cross-section of 1002 informal caregivers. Vulnerable caregivers with poor health or a serious health condition were compared with nonvulnerable caregivers.

**Results.** Thirty-six percent of caregivers were vulnerable. Compared with nonvulnerable caregivers, vulnerable caregivers were more likely to have difficulty providing care, to provide higher-intensity care, to report that their physical health had suffered since becoming a caregiver, to be aged 65 years or older, to be married, and to have less than 12 years of education.

**Conclusions.** Reliance on informal caregivers without considering the caregiver's ability to provide care can create a stressful and potentially unsafe environment for the caregiver and the care recipient. (*Am J Public Health.* 2002;92:409-413)

sentative cross-section of 4874 households between May and September 1998.<sup>20</sup> Eligibility for study inclusion was restricted to persons aged 18 years or older who were directly providing unpaid care or arranging for paid care to a relative or friend at any time during the 12 months preceding the study. A randomly selected respondent within each household who met the aforementioned eligibility criteria completed a structured, pre-tested survey questionnaire. Interviews were conducted in English or Spanish and lasted, on average, 24 minutes.

After initial screening, 83% (n=1002) of individuals who met the eligibility criteria gave verbal consent to participate in the study. For the purposes of this study, informal caregivers who reported being in fair to poor health or having a serious health condition (vulnerable caregivers) were compared with caregivers without these characteristics (nonvulnerable caregivers).

### Data Collection

Trained interviewers collected data on a wide range of information, including the following: (1) sociodemographic characteristics (e.g., age, sex, race), (2) characteristics of relationship between caregiver and care recipient (e.g., family or nonfamily, whether or not pri-

mary caregiver, living arrangement), (3) type of care provided (e.g., activities of daily living and instrumental activities of daily living), (4) hours per week of care provided, (5) duration of care, (6) caregiving intensity (we used the Level of Care Index,<sup>16</sup> a composite variable that combines the number of activities of daily living and instrumental activities of daily living performed with the hours of care provided per week to generate a score on a 5-point scale in which 1=least intensive and 5=most intensive), (7) help received from formal care providers (i.e., paid professionals or nonprofessionals), (8) perceived difficulty of providing care (we used a scale ranging from 1=very difficult to 4=not at all difficult), (9) unmet needs in providing care, (10) effect of caregiving on the caregiver's health (we used a scale ranging from 1=strongly agree to 5=strongly disagree), and (11) the caregiver's and care recipient's health status.

### Statistical Analysis

Descriptive statistical analyses, bivariate analyses, and multivariate regression analyses were performed. We used logistic regression to model vulnerable caregivers (0=no, 1=yes) as a function of unmet needs in providing care (0=no, 1=yes), difficulty providing care (0=not at all or not very, 1=some-

what or very), caregiving intensity (0=lower intensity, score of 1–3, 1=higher intensity, score of 4–5), caregiver reporting that own physical health has suffered since becoming a caregiver (0=disagrees or strongly disagrees, 1=agrees or strongly agrees), being a primary caregiver (0=no, 1=yes), caregiver's age (0=younger than 65 years, 1=65 years or older), sex (0=male, 1=female), marital status (0=not married, 1=married), race (0=White, 1=non-White), education level

(0=high school graduate or more, 1=less than high school graduate), employment status (0=unemployed, 1=employed), controlling for the care recipient's health (0=good or excellent, 1=fair or poor). Crude and adjusted odds ratios, 95% confidence intervals, and *P* values were computed. All of the analyses were weight adjusted to represent the general population.<sup>21–23</sup> Poststratification weight adjustments ranged from 0.05 to 7.76 and were derived by using 3 respondent

characteristics (age, sex, and race).<sup>20</sup> Marginal distributions were estimated with 1996 population estimates generated by the Bureau of the Census.<sup>24</sup>

## RESULTS

### Descriptive Analysis

*Sociodemographic and relational characteristics of caregivers.* Thirty-six percent of the caregivers surveyed were identified as vulnerable; that is, they reported being in fair to poor health or having a serious health condition. Vulnerable caregivers were more likely than nonvulnerable caregivers to be at least 65 years old, female, and married; to have less than a high school education; and to be primary caregivers (Table 1). However, vulnerable caregivers were less likely than nonvulnerable caregivers to be employed and to be caring for someone who lived alone.

*Activities and challenges of caregivers.* Vulnerable and nonvulnerable caregivers did not differ greatly in terms of the types of activities of daily living and instrumental activities of daily living care they provided (Table 2). The only notable differences in activities of daily living care provided by the 2 groups were bathing, dressing, and transferring, with vulnerable caregivers more likely than nonvulnerable caregivers to be providing these types of care. In addition, differences in the provision of instrumental activities of daily living revealed that vulnerable caregivers were more likely than nonvulnerable caregivers to make telephone calls on behalf of the care recipient, to manage the care recipient's finances, and to help the care recipient with obtaining assistance from governmental programs (e.g., Medicare, Supplemental Security Income). Moreover, vulnerable caregivers were more likely than nonvulnerable caregivers to provide care for 20 or more hours per week.

Although both vulnerable and nonvulnerable caregivers were equally unlikely to have help from formal care providers, vulnerable caregivers were more likely to experience difficulty with providing care, to have unmet needs in providing care, and to report that their physical health had suffered since becoming a caregiver.

**TABLE 1—Sociodemographic and Relational Characteristics of Informal Caregivers**

Characteristic	Nonvulnerable n (%)	Vulnerable n (%)	OR (95% CI)	<i>P</i>
<b>Sociodemographic Characteristics</b>				
Age, <sup>a</sup> y				
<65	629 (94)	292 (77)	(Referent)	
≥65	42 (6)	89 (23)	4.57 (3.01, 6.76)	.001*
Sex <sup>a</sup>				
Male	341 (50)	150 (39)	(Referent)	
Female	337 (50)	233 (61)	1.57 (1.21, 2.03)	.001*
Race <sup>a,b,c</sup>				
White	521 (77)	296 (77)	(Referent)	
Black	71 (11)	50 (13)	1.24 (0.84, 1.83)	.279
Hispanic	69 (10)	31 (8)	0.79 (0.51, 1.24)	.303
Marital status <sup>a,b</sup>				
Not married	287 (43)	136 (36)	(Referent)	
Married	388 (57)	247 (65)	1.34 (1.04, 1.74)	.025*
Education level <sup>a,b</sup>				
≥High school graduate	585 (87)	285 (74)	(Referent)	
<High school graduate	89 (13)	98 (26)	2.26 (1.64, 3.11)	.001*
Employment status (part- or full-time) <sup>a,b</sup>				
Unemployed	186 (28)	203 (53)	(Referent)	
Employed	491 (73)	89 (38)	0.33 (0.26, 0.43)	.001*
<b>Relational Characteristics</b>				
Affiliation with care recipient				
Family	594 (88)	340 (89)	(Referent)	
Nonfamily	84 (12)	43 (11)	1.12 (0.76, 1.65)	.575
Primary caregiver				
No	333 (54)	141 (41)	(Referent)	
Yes	290 (46)	204 (59)	1.66 (1.27, 2.17)	.001*
Care recipient's living arrangement				
Lives with caregiver	181 (27)	122 (32)	(Referent)	
Lives alone	265 (39)	123 (32)	0.69 (0.50, 0.94)	.020*
Other	228 (34)	139 (36)	0.90 (0.66, 1.24)	.528

Note. OR = crude (unadjusted) odds ratio; CI = confidence interval.

<sup>a</sup>Data have been weight adjusted.

<sup>b</sup>Results reported on available data; less than 1% of participant data are missing.

<sup>c</sup>Participants of other racial backgrounds (n = 17) were excluded.

\*Statistically significant (Cochran Mantel-Haenszel  $\chi^2$  test).

**TABLE 2—Activities and Challenges of Informal Caregivers**

Variable	Nonvulnerable n (%)	Vulnerable n (%)	OR (95% CI)	P
<b>Caregiver Activities</b>				
Type of care provided <sup>a,b</sup>				
ADLs				
Bathing	139 (22)	112 (32)	1.68 (1.25, 2.25)	.001*
Dressing	226 (36)	182 (52)	1.96 (1.50, 2.56)	.001*
Feeding	97 (15)	67 (19)	1.31 (0.93, 1.84)	.127
Incontinence	99 (16)	70 (20)	1.35 (0.96, 1.89)	.085
Transferring	239 (38)	157 (45)	1.34 (1.03, 1.75)	.030*
Ambulating	210 (33)	126 (36)	1.14 (0.87, 1.50)	.348
IADLs				
Shopping	564 (83)	335 (88)	1.41 (0.98, 2.03)	.063
Housework	487 (72)	268 (70)	0.91 (0.69, 1.20)	.505
Preparing meals	388 (57)	240 (63)	1.25 (0.97, 1.62)	.084
Transportation	514 (76)	289 (76)	0.99 (0.74, 1.32)	.930
Telephone calls	384 (57)	245 (64)	1.36 (1.05, 1.76)	.020*
Managing finances	290 (43)	222 (58)	1.87 (1.45, 2.41)	.001*
Government program assistance	175 (26)	138 (36)	1.60 (1.22, 2.10)	.001*
Provides ≥20 h/wk of care <sup>a,b</sup>	225 (35)	183 (49)	1.79 (1.38, 2.33)	.001*
Has been providing care for ≥1 y	531 (79)	294 (77)	0.92 (0.68, 1.24)	.571
<b>Caregiver Challenges</b>				
Has no help from formal caregivers <sup>a,b</sup>	550 (82)	295 (77)	0.76 (0.56, 1.04)	.087
Has difficulty providing care <sup>a,b</sup>	253 (37)	198 (52)	1.78 (1.38, 2.29)	.001*
Has unmet needs in providing care <sup>a,b</sup>	105 (15)	86 (22)	1.58 (1.15, 2.16)	.005*
Reports that physical health has suffered since becoming a caregiver	98 (15)	119 (32)	2.63 (1.94, 3.70)	.001*

Note. OR = crude (unadjusted) odds ratio; CI = confidence interval; ADL = activities of daily living; IADL = instrumental activities of daily living.

<sup>a</sup>Data have been weight adjusted.

<sup>b</sup>Results reported on available data; less than 1% of participant data are missing.

\*Statistically significant (Cochran Mantel-Haenszel  $\chi^2$  test).

week, and over one third reported that their physical health had suffered since becoming a caregiver. Moreover, vulnerable caregivers were more likely than nonvulnerable caregivers to be providing higher-intensity care and to be aged 65 years or older. Yet vulnerable caregivers were no more likely than nonvulnerable caregivers to have received help from paid support services for their care recipients. Nearly 4 of every 5 caregivers in each category provided care without paid assistance even though vulnerable caregivers bore a heavier care burden and were in poorer health.

These findings paint a disturbing picture that warrants the attention of public health policymakers and health care providers. In the US health care system, the major source of paid home health care is Medicare, which limits eligibility to the elderly and to younger people with disabilities. Medicare has strict definitions of 'homeboundness,' medical necessity, and the need for intermittent rather than continuous care. Home health aide services are provided only when there is a need for skilled nursing care. Furthermore, although aide services and help with activities of daily living were once readily available to any Medicare beneficiary whose physician certified that need, recent changes in the Medicare home health payment system provide disincentives for agencies to serve individuals with long-term care needs. Consequently, the availability of Medicare as a dependable supplement to family caregiving has been dramatically reduced. Although state Medicaid programs, which unlike Medicare have legal authority to provide long-term care, could fill the gap created by Medicare cutbacks, most have a strong nursing home bias. Many Medicaid programs are quite actively engaged in "Medicare maximization"—a policy of shifting to Medicare as many home care costs as possible.

Thus, recent changes in the policy environment, combined with continued reductions in hospital and nursing home lengths of stay, suggest that pressures on unpaid caregivers are likely to increase. Reliance on informal caregivers without considering the caregivers' ability to provide care can create a stressful and potentially unsafe environment for the caregiver and the care recipient. These find-

## Multivariate Analysis

As shown in Table 3, after the care recipient's health status was controlled for, results from logistic regression analyses revealed that vulnerable caregivers were more likely than nonvulnerable caregivers to have difficulty providing care, to provide higher-intensity care in terms of more hours of care per week in conjunction with a greater number of activities of daily living and instrumental activities of daily living, to believe that their physical health suffered as a result of caregiving, to be aged 65 years or older, to be married, and to have less than 12 years of education. The findings also revealed that vulnerable caregivers were less likely than nonvulnerable caregivers to be employed.

## DISCUSSION

Informal caregivers and their advocates have created a new awareness of the challenges of caregiving in the current health care system. In addition to their roles as hands-on care providers and care managers, family caregivers also are trusted companions, surrogate decision makers, and patients' advocates. Many caregivers meet the demands of caring for a relative or friend in the midst of their own deteriorating health. In this population-based national study, 36% of the caregivers surveyed were vulnerable. Among these vulnerable caregivers, over half reported difficulty with providing care, about half were providing care for 20 or more hours per

**TABLE 3—Logistic Regression Model of Factors Associated With Vulnerability Among Informal Caregivers (n = 886)**

Predictor	Parameter Estimate ( $\beta$ )	SE	Adjusted OR (95% CI)	P
Caregiver has unmet needs in providing care	.211	.195	1.23 (0.84, 1.81)	.281
Caregiver has difficulty providing care	.331	.170	1.39 (1.01, 1.94)	.051*
Caregiver provides higher-intensity care	.351	.158	1.42 (1.04, 1.93)	.026*
Reports that physical health has suffered since becoming a caregiver	.481	.195	1.61 (1.10, 2.37)	.014*
Primary caregiver	.069	.158	1.07 (0.79, 1.46)	.660
Age $\geq 65$ y	1.083	.253	2.93 (1.78, 4.82)	.001*
Female	.066	.158	1.07 (0.78, 1.45)	.676
Married	.422	.157	1.53 (1.12, 2.07)	.007*
Non-White	.128	.182	1.14 (0.80, 1.62)	.483
Not a high school graduate	.712	.194	2.04 (1.39, 2.98)	.002*
Employed	-.606	.168	0.55 (0.39, 0.76)	.003*
Care recipient has fair/poor health	.204	.187	1.23 (0.85, 1.77)	.274

Note. OR = odds ratio; CI = confidence interval. Model regressed the vulnerability of caregivers (0 = no, 1 = yes) as a function of duration of care (0 = less than 1 year, 1 = 1 or more years), whether caregiver needs help (0 = no, 1 = yes), support from formal care system (0 = no, 1 = yes), difficulty providing care (0 = not at all/not very, 1 = somewhat/very), caregiving intensity (0 = lower intensity, score 1–3, 1 = higher intensity, score 4–5), and the caregiver's employment status (0 = unemployed, 1 = employed either part-time or full-time), adjusting for the caregiver's sex (0 = male, 1 = female), race (0 = White, 1 = non-White), education level (0 = high school graduate or more, 1 = less than high school graduate), and the care recipient's health (0 = good/excellent health, 1 = fair/poor health).

\*Statistically significant.

ings signal a need for developing a broader array of accessible, affordable, and innovative services and programs that lend support to family caregivers in their roles. Although arguments in favor of supporting caregivers are many, one large incentive is that caregivers at increased risk for mental and physical health problems are likely to become care recipients themselves, further draining limited resources for conditions that are often preventable.

The results of this study must be viewed in light of certain survey limitations specific to nonsampling error, such as nonresponse bias, coverage bias, item response bias, and question order and context effects. The margin of error for estimates in this survey was 3%. Efforts were taken to minimize sources of errors, including pilot testing the survey instrument with focus groups, devising alternative forms of the screening instrument, training interviewers, and providing extensive supervision during data collection. Moreover, up to 50 attempts were made to contact eligible participants.

This study extends previous research on caregiving in several ways. First, in contrast to

past research, which almost always has considered caregivers as 1 population, the present study separates caregivers on the basis of key health attributes that are likely to affect both the caregiver's long-term well-being and his or her ability to provide care. Second, rather than focusing primarily on the psychological burdens of caregiving, the present study examines the content, intensity, and duration of care provided by vulnerable caregivers—aspects of caregiving that could exacerbate existing vulnerabilities over time. Taken together, the results of this study suggest that more than one third of caregivers, who are a vital and increasingly important resource to the health care system, are in the precarious position of providing intense and continuing care to others while suffering from poor health themselves. The importance of addressing the needs of these caregivers should not be underestimated. ■

#### About the Authors

Maryam Navaie-Waliser and Penny H. Feldman are with the Center for Home Care Policy and Research, Visiting Nurse Service of New York, NY. David A. Gould, Carol

Levine, and Alexis N. Kuerbis are with the United Hospital Fund, New York, NY. Karen Donelan is with the Department of Health Policy and Management, Harvard School of Public Health, Boston, Mass.

Requests for reprints should be sent to Maryam Navaie-Waliser, DrPH, Center for Home Care Policy and Research, Visiting Nurse Service of New York, 5 Penn Plaza, 11th Floor, New York, NY 10001 (e-mail: maryam.navaie@vnsny.org).

This article was accepted February 23, 2001.

#### Contributors

M. Navaie-Waliser developed the conceptual framework of this study, performed data analyses, and wrote the paper. P.H. Feldman, D.A. Gould, C. Levine, and A.N. Kuerbis contributed to the conceptual and analytic frameworks of the study. K. Donelan planned the study, designed the survey instrument, and supervised data collection.

#### Acknowledgments

This research was funded by the Henry J. Kaiser Family Foundation with supplemental support from the United Hospital Fund and the Visiting Nurse Service of New York.

An earlier version of this paper was presented at the annual meetings of the Association for Health Services Research, Los Angeles, Calif, June 2000, and the American Public Health Association, Boston, Mass, November 12–16, 2000.

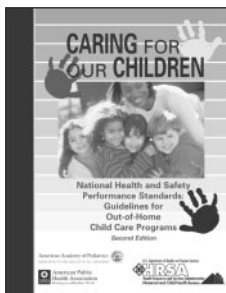
We thank Dr Timothy Peng for his insightful comments.

#### References

- Schulz R, Quittner AL. Caregiving for children and adults with chronic conditions: introduction to the special issues. *Health Psychol*. 1998;17:107–111.
- Ory MG, Hoffman RR III, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist*. 1999;39:177–185.
- Levine C. The loneliness of the long-term caregiver. *N Engl J Med*. 1999;340:1587–1590.
- Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Aff*. 1999;18:182–188.
- Mastrian KG, Ritter C, Deimling GT. Predictors of caregiver health strain. *Home Health Nurse*. 1996;14:209–217.
- Aranda MP. The influence of ethnicity and culture on the caregiver stress and coping process: a sociocultural review and analysis. *Gerontologist*. 1997;37:342–354.
- Haley WE, West CAC, Wadley VG, et al. Psychological, social and health impact of caregiving: a comparison of black and white dementia family caregivers and noncaregivers. *Psychol Aging*. 1995;10:540–552.
- Gallagher D, Rose J, Rivera P, Lovett S, Thompson LW. Prevalence of depression in family caregivers. *Gerontologist*. 1989;29:449–456.
- Schulz R, Newsom J, Mittelmark M, Burton L, Hirsch C, Jackson S. Health effects of caregiving: The Caregiver Health Effects Study: an ancillary study of the cardiovascular health study. *Ann Behav Med*. 1997;19:110–116.
- Mui AC. Perceived health and functional status

among spouse caregivers of frail older persons. *J Aging Health*. 1995;7:283–300.

11. Scharlach AE, Midanik LT, Runkle MC, Soghikian K. Health practices of adults with elder care responsibilities. *Prev Med*. 1997;26:155–161.
12. Schulz R, Beach SR. Caregiving as a risk factor for mortality. *JAMA*. 1999;282:2215–2219.
13. Shaw WS, Patterson TL, Semple SJ, et al. Longitudinal analysis of multiple indicators of health decline among spouse caregivers. *Ann Behav Med*. 1997;19:101–109.
14. Connell CM, Gibson GD. Racial, ethnic, and cultural differences in dementia caregiving: review and analysis. *Gerontologist*. 1997;37:355–364.
15. Strawbridge WJ, Wallhagen MI, Shema SJ, Kaplan GA. New burdens or more of the same? Comparing grandparent, spouse and adult-child caregivers. *Gerontologist*. 1997;37:505–510.
16. National Alliance for Caregiving (NAC) and American Association for Retired Persons. *Family Caregiving in the US: Findings From a National Survey*. Washington, DC: NAC; June 1997.
17. Haley WE, Roth DL, Coletan MI, et al. Appraisal, coping, and social support as mediators of well-being in black and white family caregivers of patients with Alzheimer's disease. *J Consult Clin Psychol*. 1996;64:121–129.
18. Martire LM, Stephens MA, Atienza AA. The interplay of work and caregiving: relationships between role satisfaction, role involvement, and caregivers' well-being. *J Gerontol B Psychol Sci Soc Sci*. 1997;52:S279–S289.
19. Song L, Biegel DE, Milligan SE. Predictors of depressive symptomatology among lower social class caregivers of persons with chronic mental illness. *Community Ment Health J*. 1997;33:269–286.
20. Levine C, Kuerbis AN, Gould DA, Navaie-Waliser M, Feldman PH, Donelan K. *Family Caregivers in New York City: Implications for the Health Care System*. New York, NY: United Hospital Fund; 2000.
21. Deming WE, Stephan FF. On a least square adjustment of a sampled frequency table when expected marginal totals are known. *Ann Math Stat*. 1940;11:427–444.
22. Bishop YMM, Fienberg SE, Holland PW. *Discrete Multivariate Analysis: Theory and Practice*. Boston, Mass: MIT Press; 1975.
23. Fienberg SE. *The Analysis of Cross-Classified Categorical Data*. 2nd ed. Boston, Mass: MIT Press; 1980.
24. *March Current Population Survey, 1996. Estimates of the Population of Counties 1990–1996*. Washington, DC: Bureau of the Census; 1996.



## 2nd Edition

ISBN 0-97156-820-0  
2002 ■ 544 pages  
Softcover

\$24.50 APHA Members  
\$34.95 Nonmembers  
plus shipping and handling



## Caring For Our Children: National Health and Safety Performance Standards for Out-of-Home Child Care

**C**aring for Our Children is the most comprehensive source of information available on the development and evaluation of health and safety aspects of day care and child care centers. The guidelines address the health and safety needs of children ranging from infants to 12-year-olds. This field-reviewed book provides performance requirements for child care providers and parents, as well as for regulatory agencies seeking national guidelines to upgrade state and local child care licensing.

The second edition is extensively revised based on the consensus of ten technical panels each focused on a particular subject. The book includes eight chapters of 658 standards and a ninth chapter of 48 recommendations for licensing and community agencies and organizations.



### American Public Health Association

#### Publication Sales

**Web:** [www.apha.org](http://www.apha.org)  
**E-mail:** [APHA@TASCO1.com](mailto:APHA@TASCO1.com)  
**Tel:** (301) 893-1894  
**FAX:** (301) 843-0159

CAR02J1